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ABSTRACT

The purpose of this quality of life training curriculum is to enhance staff's understanding of the concepts of choice, integration, and advocacy; the importance of these qualities; and how staff can promote these qualities within the daily lives of persons with developmental disabilities. The curriculum includes topics for group discussion and activities as well as individual exercises, and staff are expected to learn from each other's experiences through facilitation. The section on choice discusses how choices allow individuals to take control of their lives, encourages analysis of the choice-making opportunities of persons with disabilities, and offers suggestions for teaching choice-making. The section on integration offers principles of community integration and guidelines for promoting integration. The section on advocacy emphasizes the importance of self-advocacy as a part of independence for all people, offers guidelines for helping people to become effective self-advocates, and presents suggestions on how to respond to persons acting as self-advocates. A follow-up section provides a form for evaluating how thoroughly the qualities of choice, integration, and advocacy have been woven into the lives of persons with disabilities being served. The form covers daily activities, general lifestyle issues, and individual program planning processes. (JDD)

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Quality of Life Training Curriculum

Choice Integration Advocacy

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Developed Through the Choice & Integration Project

Kathleen Carmody
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Funded through a Grant From the
Illinois Planning Council on Developmental Disabilities

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Introduction

The purpose of the Quality of Life Training Curriculum is to enhance staff's understanding of the concepts of choice, integration and advocacy, and how they can promote these qualities within the daily lives of persons with disabilities. This Curriculum will assist staff persons in recognizing the importance of these qualities and provide ideas and strategies for staff to use in incorporating them into the lives of people with whom they work. (**Note: the phrase "people with whom you work" appears frequently throughout the training curriculum. This phrase applies to persons with disabilities whom staff persons serve, not co-workers**).

The material contained within this Curriculum is intended to be presented by a person who has already been trained in it. The format encourages group discussion and activities, as well as individual exercises. Staff are expected to learn from each other's experiences and insights; hence proper facilitation is critical to maximizing the impact of each training session. Each of the three topics averages three hours for proper presentation and discussion.

Though the Training Curriculum is targeted toward staff persons, the main focus of the materials is persons with disabilities and the kind of lifestyle which they lead. Staff are encouraged to consider the tremendous influence they exert in this area, and how they can redirect their time and resources toward goals and activities which help persons with disabilities to achieve a more desirable lifestyle.

The contents of this product were developed under a grant from the Illinois Planning Council on Developmental Disabilities. However, these contents do not necessarily reflect the policy of that agency.

CHOICE

Choice

The dictionary defines "**choice**" as:

> **1.** The act of choosing; selection. **2.** The power, right, or liberty to choose; option. **3.** A person or thing that is chosen. **4.** A number or variety from which to choose. **5.** Something that is best or preferable above others; the best part. **6.** An alternative.

The opportunity to make choices is something most people value. The opportunity and ability to make choices allows us to shape our activities and environment into the kind of a lifestyle that we desire. We can choose to live in a city or a small town; work full or part-time; go on a vacation or save money; etc.

While most of us can probably think of things which would enable us to improve or enhance our lifestyle (e.g. more money, more education, fewer family responsibilities, etc.), we would have to agree that at some point in our lives, we made choices which resulted in our leading the lifestyle which we have today.

The dictionary defines "lifestyle" as:

> A way of life or style of living that reflects the attitudes and values of an individual or a group.

Think about your lifestyle and some of the attitudes and values that it reflects. Whose attitudes and values are these?

Group Activity - Discussion

Each member of the group identifies two or three situations which define their lifestyle (e.g. going to school, raising children, likes nightlife, etc) and how this influences their lifestyle (e.g. limited free time to pursue other interests, interests lead to meeting new people, etc). Finally, have the group discuss whose attitudes and values their lifestyle reflects - their own, someone else's, an institution's (e.g. church, fraternity, etc.). Have those persons who feel their lifestyle reflects someone else's attitudes and values explain.

In addition to influencing our lifestyle, the choices we make allow us to take control over our lives. Imagine for a moment, that all of a sudden, you no longer had control over your every day, routine life. Think of all the decisions you've already made today - what time to get up; what to eat for breakfast; which clothes to wear; who you would ride to work with; whether you would call in sick; etc. How would it feel to have some one else make each of those decisions for you?

Choices for People with Disabilities

Many people with disabilities have had little opportunity to make choices in their lives. They are told with whom they will live, what they will eat, when they will be dressed, where they can and cannot go, and why they must follow program plans which others developed for them.

Go back to the earlier definition of lifestyle and think about the people with whom you work (persons who receive services from your agency).

- What kind of a lifestyle do they lead?
- Whose attitudes and values are reflected in their lifestyle?
- Do they have a lifestyle that you would consider desirable?

Group Activity - Discussion

Each member of the group identifies two or three situations which define the lifestyle of people with whom they work (e.g. attending workshop, living at residential facility, etc.) and how this influences their lifestyle (e.g. limited income, restrictions on freedoms, etc). Finally, have the group discuss whose attitudes and values are reflected in the lifestyle of people served by the agency.

Staff persons play an important role in determining how much choice people with disabilities have in their lives

Every day life is filled with opportunities to make choices. Think of the last shift you worked. Did any situations arise where you made a decision or choice for someone, rather than use the opportunity to allow someone to make a decision or choice for themself? Think of the choices you have made for yourself already today. Have the people with whom you work been able to make choices in these areas as well? Have their options been more limited than yours are? Is this necessary?

Individual Activity - Exercise

The purpose of this exercise is to think about the kind of lifestyle the people you provide services to have, and the kinds of choices they are allowed to make. First however, it may be helpful to think about your own life.

People	Possessions	Places	Activities
1.			
2.			
3.			
4.			
5.			

In the space above, identify:

- the people with whom you live (e.g. spouse, children, roommate)
- five things you own which give you pleasure (e.g. car, stereo, pet)
- five places you have gone during the past week (e.g. store, restaurant, work, health club)
- five activities you did over the week-end (e.g. attend church, clean house, visit friends)
- put an * next to each of those things which you at some point chose (e.g spouse, roommate, job, church)

Now select one person with a disability whom you know and repeat the exercise for them.

People	Possessions	Places	Activities
1.			
2.			
3.			
4.			
5.			

Who do the people you provide services to live with? What do they do on the week-ends? What kinds of things do they own? What choices have they really been able to make in their lives? As a follow-up to this exercise, try asking the person you chose to answer these questions for themself.

Adapted from: Nonaversive Intervention for Behavior Problems. Meyer, Luanna and Evans, Ian. Brookes Publishing. Baltimore; Maryland 1989

Discussion Questions

- Why is making choices important for people with disabilities?
- Isn't it easier for a staff person to make a choice for someone?
- Do people with disabilities really care if they get to make choices?
- Why haven't people told us they want to make more choices if this is how they feel?

Teaching Choice-Making

People learn by doing

We've all learned how to make choices from past lessons, from experiencing both the positive and negative consequences of our choices and from assuming increasing responsibility for control of our lives.

People with disabilities learn to make choices and decisions in this same way. A major difference between their experiences and ours, is that they have generally not been given the opportunity or proper guidance to express their choice and make decisions. An important activity for staff is to create opportunities for persons with disabilities to make choices in their lives, as well as provide guidance to people while they are learning to become capable decision-makers.

Creating Opportunities for People to Make Choices

What are some ways we can help people to make more choices and assume more control in their lives? Should we encourage people to make major life decisions on their own, when they've never even made routine decisions? Should we stand back and not interfere when people make choices which we believe to be harmful or dangerous? What if people are offered choices but they choose to keep everything the same? What if people can't decide what their choice is, or don't understand that they are being offered a choice?

Creating opportunities for people to make choices is a very simple activity. All it means is recognizing situations where options are available to a person, and taking advantage of the opportunity to create a choice-making activity. Eventually, making a choice in that situation may no longer need to be a formal "activity" for that person, but something they do as naturally as you or I would. Remember, **people learn from doing**. Other people however, may continue to rely upon you to prompt them into making a choice or may be expressing their preferences through behavior rather than through verbal communication. Continuing to present people with the opportunity to make choices is still important in these situations because **people are being given some control over their lives**.

What are some steps that we can take to assist people with disabilities to recognize and take advantage of opportunities to make choices? Imagine you were going to buy a new car. You have several options available to you. Which one you choose will depend on several variables: how much money you can spend; what your driving needs are; whether you'll be sharing the car with someone else, etc. In order to sort out the various issues related to buying a car, you go through some sort of a process - a choice-making process. You can use this same process to assist people with disabilities to make choices in their lives, whether the choice with which they are faced is as significant as where to live or as routine as which color sweater to buy.

Making Choices

1. The person should be aware/understand that a decision about a particular matter must be made.

2. The person should be aware/understand that they will influence the decision to be made.

3. The person should be informed of and understand what options are available and realistic.

4. The person should be informed of and understand the positive and negative aspects of each available option.

5. The person should be informed of and understand the consequences of choosing one option over the others which are available.

6. The person should be informed that others can be consulted on the decision.

7. The person should be assured that others will act in their best interest if it is necessary for someone else to make a decision on their behalf.

Choice Checklist

Below are some routine situations in which a choice must be made. Are people with whom you work making these choices, or is some one else? Whose attitudes and values must these person's lifestyles reflect?

- ✓ What will be eaten for meals
- ✓ Who will prepare meals
- ✓ Which household chores will be done
- ✓ Who will complete household chores
- ✓ When will household chores be completed
- ✓ What time will people wake up/go to bed
- ✓ Who is invited to visit at the house
- ✓ What church do people attend
- ✓ Who does household and personal shopping
- ✓ Who makes arrangements for transportation
- ✓ What involvement is there with neighbors and local organizations
- ✓ How is "down time" spent
- ✓ How are disputes resolved
- ✓ Where do people go at night and on the week-end
- ✓ Who answers the telephone
- ✓ Who answers the door
- ✓ Who opens and pays the bills
- ✓ Who shares bedrooms together
- ✓ Do people ask permission to do things (e.g. have a snack, go for a walk)
- ✓ How is training conducted

Individual Activity - Exercise

Select two persons who you provide services to.

1.

2.

Identify two choice-making opportunities which presently exist in their daily life in which they are not the decision maker.

1.	1.
2.	2.

Identify the reason for each person not making choices in each situation (e.g. the person doesn't recognize the opportunity to make a choice, does not know what options are available, someone else has made the choice for them, etc).

1.	1.
2.	2.

Describe what you will do to assist each person to participate in making choices in this situation

1.	1.
2.	2.

Bad Choices

What do we do if someone makes a choice which we think is bad for them? Do we intervene, or let them experience the negative consequences of their choice and hope they learn from it? Unfortunately, there are no "rules" to guide our behavior in situations such as these. Rather, we must rely upon our own past experiences and common sense.

Is the person making a choice which may endanger their own life or that of some one else? If so, how should we react? A good rule-of-thumb is thinking about how we would react to a friend in the same circumstances. Would we tell them what to do, punish them or restrict their privileges, or would we discuss the various options available to them in their particular situation, and advise them about which may be the best? And what if our friend still chose a potentially life threatening option? We may decide that a stronger intervention is necessary and pursue that.

The point is, that people with disabilities are like most other people. They do not intentionally seek out life-threatening situations. Our responsibility as staff is to ensure that people make as many decisions as they are capable of making, and receive support appropriate to their needs to make decisions for which they need assistance.

It is also important to examine whether a person's choice will be harmful to them, or will only produce negative consequences for them. Spending all of one's monthly disposable income on the first of the month will probably produce some negative consequences (e.g. no spending money for the rest of the month), but is not necessarily harmful. More important, does the person understand in real terms the consequences of their behavior? Have staff offered to assist the person in planning a monthly budget? Does the person have sufficient opportunities to spend money during the month? Does the person understand the relationship between saving money and being able to

acquire desirable things? Does the person have a monthly income which is sufficient to allow him/her to obtain the things they want?

Our role as staff is to ensure that people not only make choices, but make informed choices. If they make an informed decision with which we disagree, the negative consequences of that decision may be a far better learning experience than our intervening and making the person's decision for them.

Some Final Things to Think About

People learn from doing - they learn what they like and don't like. People cannot say what their choice or preference is without experience. A lifetime of limited experience cannot be undone in a few months. An important part of helping people to make choices is ensuring that they have a wide variety of experiences upon which to base decisions.

Remind Yourself and Tell Others

ALL CHOICES ARE IMPORTANT

Choices create opportunities for people to exert control over their lives. If the only thing a person can control in their life is the kind of cereal they eat for breakfast, or the color of their sweater, we need to ensure that they have at least that much control

ALL PEOPLE HAVE PREFERENCES

Some people may communicate their preference through behaviors rather than speech, some may rely on us and how well we know them to interpret their preference, and some people may have preferences in more areas than others - but all people have some preferences.

IT DOES MATTER

Choices do matter in the lives of people with disabilities just as they matter in our lives. The goal of our services should be to assist people in becoming as independent as possible. If we continue to make decisions for people, we teach them dependence, rather than independence.

INTEGRATION

Integration

The Minnesota Governor's Planning Council on Developmental Disabilities defines integration as:

> **1.** Living, learning, working and enjoying leisure time with and among a majority of people who are not disabled; **2.** Physical presence and participation in the community that results in valued roles such as home owner, tenant or neighbor, student, co-worker, customer, associate or friend; and **3.** Providing appropriate supports that match the person's needs, strengths, interests and preferences rather than mere placement in integrated environments.

Test Your Integration Quotient. Lippert, Toni. Minnesota Governor's Planning Council on Developmental Disabilities.

Community integration is a popular term today within the field of developmental disabilities. Different people have different ideas about what it means, and how it can be achieved. Some people define integration according to the setting in which it occurs (e.g. shopping for food at the grocery store). Others define integration by the number of persons involved in an activity (e.g. going to a movie with one person versus eight people). Finally, integration is sometimes defined by the activity in which a person is involved (e.g. volunteering at a local hospital). Each of these are a part of what integration for people with disabilities should mean. Our challenge is to understand how the concept of integration relates to our role as a staff person, and to assist people to achieve maximum integration in their lives.

Integration is an important quality in the lives of persons with disabilities. Many people with disabilities have had limited opportunities and experiences. They probably live with others who have a disability, work with others who have a disability and socialize with others who have a disability. These may not necessarily be bad opportunities or experiences, but we must recognize that they are extremely limiting. One reason why community integration is such an important facet in the lives of persons with disabilities is that it expands their opportunities and experiences.

People learn from those around them. Integration provides the opportunity for people with disabilities to be around others who do not have disabilities. Both groups can learn from such experiences.

The following Principles of Community Integration do not concretely define the quality of integration. They should however, help further our understanding of why integration is important, and how we can help foster it. If you agree with these principles, and can think of ways in which you can operationalize them in your work, then you probably have a pretty good understanding of what is and is not integration.

Principles of Community Integration

1. **All people with developmental disabilities belong in the community.**

2. **People with severe disabilities should be integrated into to typical neighborhoods, work environments, and community settings.**

3. **Support the placement of people with severe disabilities in homes and natural community settings.**

4. **Community living arrangements should be family scale.**

5. **Encourage the development of social relationships between people with severe disabilities and other people.**

6. **Foster participation in community life and the development of community living skills.**

7. **Involve parents and consumers in the design, operation and monitoring of services.**

Reprinted from The Nonrestrictive Environment: On Community Integration for People with the Most Severe Disabilities. Taylor, Steven et al. Human Policy Press. Syracuse; New York 1987

Group Activity - Discussion

Each member of the group writes down two examples of ways in which a person with whom they work has achieved integration. The examples should include the type of activity, the number of persons involved and the setting in which it occurs. Participants then share their examples with the group. Does everyone agree on whether activities are true examples of integration? Does everyone have the same examples of integration? Can the group come to a consensus on which are examples of integration and which are not?

Type of Activity	Setting	Number
1.		
2.		

People do not always agree on what qualifies as integration. This should not be surprising, as our definition of integration is probably influenced by our values and experiences, which differ among people. We may in fact, be more able to agree on what is not integration rather than what is. While defining the term "integration" is a useful activity, it is only worthwhile as a step in the process of helping persons to attain and experience integration.

Promoting Integration

Helping people to become better integrated into their communities is a very challenging responsibility. It is also one of the most important responsibilities a staff person has. Think of eight persons with whom you work, or eight persons with a disability whom you know. Now think of what you could do to help them all become more integrated into their home and communities. It's a little overwhelming, isn't it? Unfortunately, when we think of integration, or are taught about integration, we tend to think of it in terms of relatively large numbers of people, such as eight residents of a group home, or 15 residents of an ICF-DD. This of course, immediately brings to mind one of the biggest obstacles to integration - too few staff for too many people.

Other circumstances which are often identified as obstacles to integration include:

- insufficient transportation
- unsafe transportation
- inadequate funds
- people don't know what they want to do in the community
- the community isn't ready to accept people with disabilities
- people don't know how to act in the community
- people don't want to go into the community (and shouldn't that be their choice?)
- people don't like to go into the community
- etcetera

Some of these factors help to explain why achieving integration is challenging. Some are excuses for why people have not become better integrated into their communities. None are valid reasons for giving up on integration as an important goal for each person served by your agency.

One Person at a Time

Perhaps the most important thing to remember about integration is that it is best achieved one person at a time. One of the major flaws in our efforts to help persons become better integrated has been taking a large group of people to a place in the community, and thinking that we have achieved integration.

Community integration is not accomplished merely through community presence

Though it can be frustrating and even uncomfortable, we need to consider that community integration is best achieved one person at a time. This means that we may help some people to become involved in their communities before others. It means that the quality of some people's lives will improve before others. It means that we need to assess the extent to which individual people are truly involved in their community, and think of creative strategies based on the preferences, strengths and needs of individual persons, for increasing that involvement.

The development of personal relationships with people in the community is a very important by-product of the one-person-at-a-time method. We've all had the experience of going to an event, joining an organization or taking a class, and meeting someone with whom we then became friends. People with disabilities need those same opportunities to make friends. Imagine that your activities were limited to only those that involved other people with blond hair, or blue eyes, or who attended your church. You may find friends among this group, but you could probably find friends outside of this group as well - if only you had the opportunity.

People with disabilities need friends and people whom they can count on just as everyone does. As people develop relationships with others whom they've met in the community, the staff support that person requires to participate in community-based activities is lessened. People enjoy going to the movies or to a restaurant with friends, they don't mind picking up a friend for a meeting, friends call each other on the telephone just to chat. When is the last time a neighbor stopped by your program to pick up a group of people for lunch, or someone dropped a group of people off at the program on their way into work? People tend not to become involved with persons who are in a group, but may approach or respond to a socially appropriate number of people (e.g. two adults at a store, a member of the church congregation, etc.).

People want to be surrounded by family and friends; not only persons who are paid to be with them, or whom they know only due to the similarity of their circumstances - whether it be others residing in a nursing facility, or attending a day program, or participating in special recreation activities, but friends, with whom they have more in common than just a label.

Discussion Questions

- Why is community integration important for people with disabilities?
- What are some opportunities available in your community which may not have been explored yet?
- How long does/should it take for people to become integrated into their communities?
- What if the community won't accept people with disabilities?

Individual Activity - Exercise

Select two persons who you provide services to. Identify three people other than staff (current or former) whom they could call in an emergency, or to share good news, or just to talk. No more than one of the three should be a family member.

Name:	**Name:**
1.	1.
2.	2.
3.	3.

Identify three different persons who have called the individual within the past week. The calls should be for social and not business purposes (e.g. a friend from church calling to offer a ride versus a doctor's office calling to confirm an appointment).

Name:	**Name:**
1.	1.
2.	2.
3.	3.

Select one person (one of the two identified above or another person served through your program) who does not have three persons whom they could call. Identify three strategies using community integration to help the person develop friendships.

1.

2.

3.

PROMOTING INTEGRATION

The process of integration can be promoted and supported by others. What have staff or family done in the past month for a person to support, encourage and/or facilitate social relationships and involvement in community activities?

1. Introduced him/her to neighbors and to other people in the community

2. Arranged for membership or participation in a community group, with the support of a group member

3. Emphasized training, guidance, and activities for him/her to support successful and consistent community involvements, activities and relationships

4. Spoken to neighbors and to people in community groups to encourage and facilitate individual relationships and participation in community activities

5. Provided training and feedback in social "skills" necessary for various situations

6. Provided feedback or guidance in dress and grooming for specific social situations

7. Provided training and guidance in specific skills that may be necessary to participate in a community activity (e.g. skills relating to travel, money, time, communication, etc.)

8. Provided guidance in decision-making, in how to make choices, and in self-advocacy

9. Provided training or guidance in other relevant areas (specify)

10. Family members or staff presenting themselves as positive social role models with respect to appearance, grooming, social skills, behavior, etc.

11. Encouraged and/or engineered ongoing activities in the community specific to his/her individual preference and needs to build relationships and "memberships"

12. Engineered one-to-one experiences connecting him/her with people in the community.

Reprinted from The Personal Integration Inventory, by Hank Bersani and Rebecca Salon. Research and Training Center on Community Integration, Center on Human Policy. Syracuse; New York, 1988

Integration Opportunities Within the Community

This list can be used to help people identify possible community activities in which they would like to become involved, or places which they may like to visit. You may need to think of creative ways to explain to people what the activities or places are (e.g. through pictures, visiting places)

Laundromat	Grocery store	Go to sporting events	Go for walks
Barber shop	Shopping mall	Watch sports on tv	Swim
Beauty parlor	Bus stop	Read books	Go shopping
Doctor's office	Movie theater	Play sports	Go to plays
Library	Pharmacy	Watch television	Attend concerts
Park	Restaurant	Listen to the radio	Attend art fairs
Health club	Dentist office	Go to the movies	Visit friends
Church	Bank	Watch videos	Volunteer
Community theater	Attend YMCA/YWCA	Join Jaycees	Take a class

Persons with Severe Disabilities

An additional issue to consider is how important a factor the person's level of disability is or should be to their opportunities for community integration. Do people with severe disabilities understand integration? How can people with behavior problems be integrated into the community? What about people who like what they're doing now and don't want to do anything different?

Community integration is not a goal which should be pursued only for "the high functioning", or "the ambulatory" or "the verbal" . Community integration is an essential quality which should be a part of every person's life. The friendships that can result from community integration opportunities are important for everyone. The skills gained through experiences in the community are useful to all persons.

The level of a person's disability should be irrelevant when considering the options for community integration. People with disabilities, and particularly those whose disabilities are more severe, have enough limitations placed upon them already without us adding an additional one. We must imagine the possibilities for people, and then think of ways to support people in attaining what is possible.

A PERSON WITH A SEVERE DISABILITY CAN BECOME AS INVOLVED IN THEIR COMMUNITY AS A PERSON WITH A MILD DISABILITY. THE LEVEL OF SUPPORT NECESSARY TO ATTAIN WHAT IS POSSIBLE MAY VARY, THE CREATIVITY REQUIRED TO CREATE OPPORTUNITIES FOR COMMUNITY INTEGRATION MAY VARY, BUT THE POSSIBILITIES AND EXPECTATIONS FOR PEOPLE SHOULD NEVER VARY.

Group Activity - Discussion

Consider Jill and Ed, described below. What are their lives like? Do they have what others would consider to be a "desirable lifestyle"? What do we know about them and their experiences which can help us to identify and facilitate possible community integration opportunities? If Jill or Ed were the "one person at a time" with whom you were helping to achieve integration, what would you do?

Jill

Jill is a 23 year old woman living in a group home with 7 other people. She has been living in the group home for two years. Before moving to the group home Jill lived for two years at an ICF-DD < 15 in the same town, and before that, with her parents and two brothers. Jill attends a Developmental Training Program five days a week, where her goals include attending to tasks, learning to recognize and count coins, sorting objects by shape (pre-vocational activity) and learning appropriate grooming skills. Jill enjoys watching television and listening to the radio (Top 40 stations) alone. She likes looking at fashion magazines, but is unable to read them. Staff of the group home feel she probably does not really understand the magazines. Jill goes to the mall with staff and other residents from the group home on the week-ends, and seems to enjoy window shopping. Jill will often try to wander off in the mall unaccompanied, and is sometimes found talking to strangers (even though her vocabulary is very limited). Jill has one friend, another woman with a disability with whom Jill went to school. Jill's friend is higher functioning and has a Supported Employment job. Jill sometimes cannot do things with her friend because she doesn't have as much money. Events that Jill seems to have enjoyed in the past include attending a dance performance, visiting her grandmother, helping her mother at a bake sale for her younger brother's kindergarten class, shopping for clothes and attending a week-end retreat for young adults with disabilities sponsored by a local church (even though Jill does not attend mass regularly).

Ed

Ed is a 54 year old man who lives in an apartment with one other man who also has a disability. Ed and his roommate have a worker with them from 4:00 p.m. to 9:00 p.m. every day, and from 8:00 a.m. to 9:00 p.m. on week-ends. They can call staff at the group home which is a half a mile away if any problems arise when staff are not there. Ed has lived in his apartment for the past year and a half; before that he lived in a group home for five years, and before that he lived in a state facility for 13 years. Ed works at the local sheltered workshop, which he has attended for the past 12 years. Ed can remember simple directions, and has made significant progress in learning to cook, which he says he enjoys. He attends church every Sunday. The staff person walks with Ed to church and picks him up when the service is over. Ed and his roommate go bowling with their friends from the group home every Saturday afternoon, (the manager gives them a discount because they've been coming for so long). Ed enjoys playing checkers and bingo. Staff once suggested he go to bingo night at his church, but Ed said he wasn't interested. Ed seems to prefer interacting with people one-to-one rather than in larger groups, which is why he was chosen to move out of the group home. Ed knows two of his neighbors; an elderly woman and a man about 10 years younger than Ed who is often in his driveway fixing his car or playing ball with his two young sons. Ed says hello to these two neighbors while walking to the corner every evening (one of Ed's goals is to lose weight, so he walks to the corner and back every night after dinner for exercise).

Some Final Things to Think About

Remind Yourself and Tell Others

ALL PERSONS WITH DISABILITIES CAN BENEFIT FROM THE COMMUNITY

Opportunities to become involved in non-segregated activities within the community should be available to all persons with disabilities. People with disabilities have enough restrictions placed upon them without us adding our own.

ONE PERSON AT A TIME

Community integration is best accomplished one person at a time. You cannot realistically provide the same degree of assistance to several people at once, unless you have no other job responsibilities. Do a good job of assisting one person and then move onto the next, rather than spread yourself too thin, which will accomplish nothing.

PEOPLE NEED EXPOSURE TO COMMUNITY OPPORTUNITIES

Persons with disabilities may not be aware of opportunities in the community, may not understand some of the opportunities, or may not know what they like to do. Take people into the community and expose them to what is possible. If they don't like one experience, they can try something different next time.

PEOPLE MAY BE SCARED

The "community" is a foreign place to many people with disabilities. Do not expect people to immediately immerse themselves in it after a lifetime of seclusion from it. Help people to make friends, accompany them to events, explore the many options with them - don't ever accept that people with disabilities don't belong or don't want to belong in the community.

ADVOCACY

Advocacy

The Brown County Association for Retarded Citizens defines self-advocacy as:

Advocacy by an individual whose rights are at risk of being violated or diminished, in order to represent his/her own rights and interests and speak on his/her own behalf.

Charting a Bold New Course: A Self Advocacy Curriculum. DeMerit, Karen et al., Brown County Citizen Advocacy; Brown County Association for Retarded Citizens. Green Bay; Wisconsin, 1988

The Technical Assistance for Self-Advocacy Project describes self-advocacy as:

> Self-advocacy can be an individual or collective action. On an individual level, self-advocacy may mean something as basic as being given the opportunity to choose what clothes one wants to wear; such action may match one individual's maximum level of current skill capacity. For another person, self-advocacy may mean learning to play an instrument, learning to use a sub system, working in the local community, working with a special-interest group, writing a Congress person or testifying before the legislature.

Basically, self-advocacy encompasses knowing your rights and responsibilities, standing up for your rights, taking responsibility for your life.

On a collective level, groups of handicapped people have organized on local, state and national bases. They have promoted the assets, needs and problems associated with the disabled to the general public, the government and the private sector. Opportunities to make friends, share skills, learn teamwork and socialize are also important elements. Self-advocacy groups are also known as peer support groups, mutual-aid and self-help groups.

An Advisor's Guidebook for Self-Advocacy. Woodyard, J. Technical Assistance for Self-Advocacy Project, UAF - University of Kansas. 1980

As you can see, self-advocacy is a term which can describe many different roles, actions and joint efforts.

You may be wondering why the topic of "self-advocacy" is being included as part of a staff training curriculum. Why not train the persons served by the agency in advocacy, and train staff on topics more related to our job? The answer to that question is that second to persons with disabilities, staff, and particularly those at the direct service level, play the most important role in determining how effective a self-advocate someone will become.

Many self-advocacy efforts are thwarted either intentionally or unintentionally, by staff. Staff may feel threatened by the increasing assertiveness of persons with whom they work. They may become indignant: "if you were so capable of making decisions for yourself you wouldn't be in this program". Or staff may simply be confused: "we thought we were doing what was best, but now are being told that people are dissatisfied with their lives, and our role within their lives - we want to do what is right, but aren't sure what that is anymore".

An important thought to keep in mind during your work day is that our job is to help people become as independent as possible and self-advocacy is an important part of independence for all people.

We practice self-advocacy every day, it's just that it has become so natural for us that we don't even think of it as a separate or deliberate action - it's just something you need to do in the community. Did you honk your horn at another car on the way to work today? Tell the butcher how you wanted your meat cut? Tell a son/daughter/brother/sister/spouse to turn off the television, turn down the radio, or pick up their things? These are all examples of self-advocacy. People with disabilities need to carry out these same types of activities if they are ever to become more independent.

WHEN WE SQUASH EXPRESSIONS OF SELF-ADVOCACY WE FOSTER DEPENDENCE, RATHER THAN PROMOTE INDEPENDENCE

Does self-advocacy mean people with disabilities can tell me how to do my job, or that they can tell me they don't have to listen to me anymore, or that they don't have to follow the rules?

Despite what your impressions of self-advocacy may be, it is not an evil plot designed to make your life or job more difficult. On the contrary, self-advocacy can become the basis for tremendous growth and learning experiences on the part of persons with disabilities. Use the opportunities that arise in this manner. If a person indicates dissatisfaction with certain circumstances or conditions, whether they be lack of adequate public transportation, not enough good paying jobs for people with disabilities or disagreement over a "house rule", use this first step in self-advocacy - identifying an issue that the person wants to do something about, as an opportunity to pursue problem solving techniques:

- What does the person see as the issue to be addressed?
- How does the issue affect their life?
- What steps do they think should be taken to address this issue?
- Should they pursue the issue with others who are also affected or act alone?
- What are the pros and cons of taking action?
- What is the next step?

Your response to people acting as self-advocates should be to recognize self-advocacy as a powerful and positive force in the lives of persons with disabilities, and using this force to further train people in and/or enable them to pursue skills which they need to become more independent.

Group Activity - Discussion

Have the group discuss the following topics. You may want to write individual responses on large paper for all to remember and discuss.

- What does self-advocacy mean?
- What are some situations you've been involved in where persons acted as effective self-advocates?
- What are some situations you've been involved in where persons acted as ineffective self-advocates? Why were they ineffective?
- How should you respond to situations where someone is being ineffective as a self-advocate?

A final issue related to how you perceive self-advocacy for persons with disabilities is whether you feel offended at the idea of persons with disabilities wanting to meet as a group, without staff involvement. Staff sometimes feel uneasy about this. There are concerns about what people are learning; whether they really understand some of the concepts of self-advocacy and how to apply these; or how people will react to this training.

This issue can best be described as the "How Come We Can't Attend Meetings" Syndrome. This typically affects staff who work directly with persons engaged in self-advocacy activities. They may feel that they have been personally betrayed because their presence is not requested or allowed at self-advocacy meetings, discussions or trainings. The reason that staff are not welcome at such activities is that people with disabilities need to feel and be in control of these activities, if they are to be successful. If staff (aside from a requested facilitator or trainer) are present, people with disabilities will not feel or be in control of the activities - it's that simple.

Helping People to Become Effective Self-Advocates

More than likely, someone with a disability that you know has been involved in a self-advocacy group, or attended some type of self-advocacy training. How can you as a staff person build upon these experiences and help him/her in their efforts to become an effective self-advocate? There are three things staff can do to help people with disabilities become more effective self-advocates:

1. **Provide informal training and encouragement to people in their efforts to become effective self advocates;**

2. **Create opportunities for people to demonstrate and experience self-advocacy;**

3. **Help people to process their experiences so that they learn from them.**

There are many skills which will enhance people's effectiveness as a self-advocate, including some which you may not immediately associate with advocacy. Enhancing people's abilities in these areas, either through informal training on the topic, by creating opportunities for practicing the skill or by discussing how someone may more appropriately respond to a situation, are all ways in which staff can use routine situations to help promote effective self-advocacy skills.

Communication: How well do people with whom you work communicate? People do not necessarily need to be verbal in order to communicate, but they do have to have some way of expressing themselves which is understandable to others. Does everyone with whom you work have some type of understandable language and means of communication (e.g. word board, sign language, behavior, etc.), even if they can only communicate a few ideas. Are people effective communicators? Do they say what they feel, or what they think we want to hear? Are they encouraged to express their ideas and opinions, even if these are unpopular, or don't seem to make sense? Is there a payoff for people when they do communicate their own ideas and opinions, or are these dismissed as impossible or impractical? Do people sit around the dinner table and discuss current events, attend adult activities in the community or have their limitations challenged on a regular basis? These are all issues related to communication which staff can address on a routine basis with people, which will contribute toward effective self-advocacy skills.

Group Processes: Many people with disabilities have never had the experience of being part of a group of equals. Identifying common concerns, delegating responsibility, waiting their turn, working with others, interacting with outside entities - these are all skills which people gain through experience. Involving people in groups (e.g. members of a household, a group within the day training program) and allowing those groups to take action is one way to help people become more effective self-advocates. Another method would be to discuss group processes with people - what makes groups work well, what makes groups work poorly, etc.

Problem Solving Techniques: Do people know and understand the steps in problem-solving? Does staff response to problems demonstrate these steps, or are they disregarded, and a quick decision made? Are people encouraged to go through these steps in routine situations?

1. **Identification** - what is the issue?

2. **Brainstorming** - what are all the possible options available to address the issue?

3. **Evaluation** - what are the positive and negative consequences of these options?

4. **Decision** - which option is chosen?

5. **Implementation** - how will this option be carried out?

6. **Action** - acting upon the decision made.

Planning Skills: People with disabilities may not know how to plan things, such as an outing, how to save money or getting a job. Teaching and allowing people to plan activities or strategies for attaining a goal, identifying the steps necessary to accomplish what they want, thinking of alternate ways that the steps could be carried out, creating a timetable for accomplishment, these are all planning skills which are useful to self-advocacy efforts.

Individual Activity - Exercise

Jim has returned from the workshop very angry and frustrated and has been banging things around the house. He is not speaking very coherently, but from what you can gather, he got into a fight with the person who sits across from him, and his supervisor once again (according to Jim), sided with the other person. As a result of this incident, Jim was not allowed to eat lunch with his girlfriend (whom he only sees at the workshop). Jim says he is going to quit the workshop tomorrow (which he must continue to attend if he wants to live in the agency residential program) and is going to call the governor and mayor. Jim has made this claim in the past; the first time it happened, he did not reach the governor or mayor, but did call a few random telephone numbers. Since this time, staff do not allow Jim to use the telephone if he is in a bad mood.

Select two of the four skill areas identified above and describe how you would use each to intervene with Jim in this situation. Be as specific as possible.

Skill Area:

Strategy:

Skill Area:

Strategy:

Discuss your responses with the group.

Recently, people with disabilities gathered to share ideas regarding self-advocacy. They were asked the question: "what works to help people speak for themselves to change their own lives?". Below are some of their responses.

A person's ability to speak for him or herself grows when others:

- **Firmly believe that the person has the right to choices, both in everyday life and in setting life goals.**
- **Do not label the person, but get to know the person for him or herself.**
- **Ask and listen with care to what the person wants, what the person's goals are, what specific help the person needs.**
- **Focus on the person's capabilities, not the person's inabilities.**
- **Match supports to the person instead of fitting the person into what's available.**
- **Encourage the person to work on what the person wants, even if it is hard to see how far the person can go toward a goal.**
- **Work along with the person to find ways to make what the person wants possible by helping with problem solving and by connecting the person with other people who can be trusted to help.**
- **Realize that the person can learn from mistakes if the person has the right to make them and the support to figure out what went wrong and how to move on.**
- **Recognize that it's okay for the person to say "I hate this. Let's start over!"**

Reprinted from Effective Self Advocacy: Empowering People with Disabilities to Speak for Themselves. Research and Training Center on Community Living, Institute on Community Integration; University of Minnesota. Report # 90-4, October 1990

How to Respond to Persons Acting as Self-Advocates

The manner in which you respond to and support people's efforts to become self-advocates will strongly influence their success. Staff may be among the first to feel the effects of these efforts, as presumably, they have the most contact with people.

Another reason staff may be the first to feel the impact of self-advocacy efforts is that they are the most immediate extension of the agency, which is probably the single greatest source of influence over the person's life. Even if, for the most part, the person is satisfied with their services and is content with their lifestyle, it should not be surprising if people dislike some aspects of agency services. Further, there will be individuals who are immensely dissatisfied with their services and their lifestyle, and have discovered that they have the right to voice their dissatisfaction and expect reasonable changes be made to accommodate their needs. Meanwhile, staff either are the targets of people's dissatisfaction, or are expected to play the role of intermediary, conveying information and policies between the administration of the agency and the people whom the agency serves.

A common reaction to these circumstances is to disregard or minimize the concerns voiced by people. Another, even more destructive reaction is to convey the attitude that people don't have the right to raise concerns about their living conditions, or how they are treated, or unmet needs, and should in fact be "grateful" for whatever services they are receiving. Of course, both of these attitudes are destructive, and in fact, persons with disabilities and their families should not be made to feel any more appreciative for their services than we should for our job (if it weren't for them, we would not be here).

Hopefully, some of the information presented earlier in this section as well as in the previous two sections should give you some ideas on how to react to persons with disabilities who are beginning to assert themselves and their rights. While recognizing that this may be a challenging position for staff to find themselves in, it is also important to remember your role as a staff person, and consider how you might respond to the situation most appropriately from a professional standpoint (which does not necessarily translate into"cold and distant"), rather than a personal or emotional standpoint. Below are some strategies and thoughts to consider which may assist you.

1. **Identify the concern.** Consider the example earlier. Was Jim upset with his workshop because his supervisor didn't side with him in a dispute? Because he doesn't like the person who sits across from him? Because he couldn't eat lunch with his girlfriend? Because he's bored? Different approaches to resolving the issue may be taken depending on which of these issues is the greatest concern. Your assistance and/or support for someone's self-advocacy efforts will be greatly diluted if you have one understanding of the issue, and the person has a different one.

2. **Separate the facts.** People may interpret self-advocacy to mean a variety of things. They may think it means they have the right to tell staff how they feel about things or they may think it means they have the right to demand things from staff and others with whom they live. Remember, self-advocacy is a new concept for many people and they may require guidance in how to apply it to real-life situations. Helping people to understand (which is a very different process and approach from simply informing people) what they can and cannot expect, and explaining their recourse when expectations will not be met, is a helpful response to some situations. Further, people need to know how to act and respond in the real world. A calm and reasonable

approach to a situation will probably yield greater results than throwing a tantrum. As staff, you have a responsibility to give people opportunities to practice these skills, as well as to respond to their efforts so that they can experience a positive pay-off.

3. **De-personalize the issue.** While not all self-advocacy efforts are directed toward staff, at some point, someone will probably raise concerns about how they are treated by staff, the activities they participate in with staff, or rules imposed upon them by staff. Some of the strategies discussed earlier (problem solving, approaching the situation as a learning experience) can help to direct the situation in a positive direction. Sometimes however, even this may not prevent one or both parties from turning the situation into a shouting match. When a situation reaches this point, the best strategy may be to wait until everyone involved is more open to discussing specific concerns.

4. **Allow people their feelings.** Sometimes, you may be confronted with an issue, concern or request which makes no sense to you. It is easy in a situation like this to quickly dismiss or disregard the other person's feelings. This is not a positive reaction to someone's expression of self-advocacy. While you may not agree with someone's position, or may have to inform someone that they cannot have or do what they want to, this is quite different from verbally attacking, minimizing, or mocking someone's request. These are never appropriate responses to an expression of self-advocacy and people should not have to fear being treated this way.

Some Final Things to Think About

Remind Yourself and Tell Others

PEOPLE DO HAVE THE RIGHT TO EXPRESS THEMSELVES

Self-advocacy occurs when people express their thoughts, desires, concerns and feelings. People have a right to this kind of expression. We should assist people to express themselves appropriately and in a manner which will help them to become effective advocates

SELF-ADVOCACY PROMOTES INDEPENDENCE

People become more independent as they become more effective self-advocates. By speaking out for themselves and their wishes, they are less reliant upon staff and others. We need to make sure that people with disabilities are capable of advocating for themselves and get the opportunity to do so in the community.

USE SELF-ADVOCACY AS A LEARNING EXPERIENCE

Self-advocacy can be used to teach many related skills, which people need to have if they are going to live in the community. Use self-advocacy as a way of teaching problem solving, communication, group processes, planning and other skills that people can use.

DON'T SQUASH SELF-ADVOCACY EFFORTS

You may find yourself unsure about how to respond to people who in the past may have been passive and accepting, but are now more inclined to express themselves. Remember, this is a good step for people. Our role is to encourage this kind of participation in life.

TRAINING FOLLOW-UP

This section is intended to review how well the qualities of choice, integration and advocacy have been incorporated into the lives of persons receiving agency services. The follow-up section focuses on lifestyle issues related to persons with disabilities, rather than individual staff person's performance. The reason for this focus is that the goal of the Curriculum is to enhance the daily lives of persons with disabilities. The method for achieving this goal is the targeted staff training which the Curriculum presents. Evaluating how thoroughly these qualities have been woven into the lives of persons with disabilities, rather than how often an individual staff person offers choices, is the true test of how effective this training has been.

The following form should be completed at least annually . The responses will suggest whether the qualities of choice, integration and advocacy are sufficiently represented in the person's life. If they are not, staff as a team, should develop a plan which addresses this critical area. This plan should be developed with the full participation of the person receiving services and should employ strategies described in the Training Curriculum.

Quality of Life Training Curriculum

Review of Staff Implementation

Activity	Has the person ever done this activity	How often does the activity occur	Who choose the specifics about this activity	How many others participate in the activity
1. Cleaning the house (or learning housecleaning skills)				
2. Handling personal banking (including deposits, withdrawals, opening accounts, etc.)				
3. Managing personal finances (establishing a budget, paying bills)				
4. Going out to eat at a fast food restaurant				
5. Going out to eat at other than a fast food restaurant				
6. Going to the library				
7. Going to a sporting event				
8. Going to a non-segregated job				
9. Taking a class at the community college or community center				
10. Cooking dinner (including planning meal, purchasing and preparing food and cleaning up)				
11. Inviting a friend over to visit				
12. Going to a friend's house to visit				
13. Attending religious services				
14. Calling a friend on the telephone				
15. Getting a phone call from a friend on the telephone				
16. Going on a date				
17. Taking a vacation				
18. Riding public transportation				

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Circumstances/situations within the person's life	Did the person actively participate in this decision	Is the person satisfied with their current situation	What steps have staff taken to help the person address this situation
1. Who the person lives with			
2. Who the person shares a room with			
3. Staff who work with the person			
4. Where the house/apartment is located			
5. The number of persons living together in the house			
6. Did the person choose the house in which they are living			
7. Furnishings and decorations within the house			
8. Schedules/routines (e.g. household chores)			
9. Determination of "house rules"			
10. Goals and objectives contained within the IHP			
11. What the person does during the daytime (e.g. DT Program, workshop, SEP, competitive employment)			
12. Particular activities the person participates in at the DT Program			
13. Skills the person is learning at the DT Program			
14. Places where the person goes on the week-end			
15. Does the person feel they have a sufficient income			
16. Is the person able to get to the places where she/he wants to go			
17. Does the person have control over her/his lifestyle			
18 Does the person have non-disabled friends			
19. Does the person participate in non-segregated, interactive recreation/leisure activities			
20. How "non-programming" time is spent			
21. What job the person has			

22. What hours the person works			
23. Whether the person works individually or as part of a "crew" (e.g. janitorial)			
24. What field the person works in (e.g. restaurants, cleaning, office)			

Individual Program Planning Processes	Staff person responsible	Was the activity carried out	What was the person's response
1. Consult the person and their family for a convenient time to hold the IDT meeting (as opposed to informing the person when the meeting will be held)			
2. Meeting with the person well in advance of the IDT meeting to review current IHP and discuss progress toward goals/objectives			
3. Meeting with the person well in advance of the IDT meeting to discuss satisfaction with current goals/objectives/activities			
4. Meeting with the person well in advance of the IDT meeting to discuss programming options available for the upcoming IHP			
5. Conducting appropriate assessments to help identify functional skills which the person needs to learn			
6. Helping the person to identify goals/objectives which they would like to have included in their IHP			
7. Preparing the person for participating in the IDT meeting (role plays, how to raise issues of concern, etc)			
8. Assisting the person to direct the IDT meeting toward issues/ areas which are of concern to her/her			
9. Preparing written items for distribution to the IDT if necessary			
10. Reviewing the IHP with the person to ensure it reflects their choices, expectations and needs			
11. Developing an "Integration Goal"			

General Lifestyle Issues	Who regularly carries out the activity	If activity is carried out by other than the person - why	What are staff doing to promote independence in this area
1. Opens mail			
2. Answers door			
3. Answers telephone			
4. Pays bills			
5. Makes shopping list			
6. Does grocery shopping			
7. Selects which clothes will be worn			
8. Decides what will be eaten for meals			
9. Resolves conflicts with another resident/program participant			
10. Decides where they will sit at DT Program			
11. Decides when to take breaks			
12. Waking up in the morning/going to bed at nights (e.g. does the person use an alarm clock, do they have a "bedtime")			
13. Choosing where to go for leisure activities			
14. Chooses whether to attend religious services and where to attend			
15. Initiates contacts to pursue friendships/interests			
16. Meeting own transportation needs			
17. Getting prescription medications filled			
18. Handling checks (e.g. acting as own payee, signing check cashing check)			
19. Handling problems which arise with benefits			
20. Resolving disputes with supervisor (at DT, workshop or job)			
21. Calling in sick to work/DT			
22. Resolving disputes with parents			

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